BASELINE QUESTIONNAIRE FOR CASES ONLY

ID No.				-			
Form Type	C	B	0	1			

General Instructions: Complete this questionnaire for all cases at baseline.

I. CASE IDENTIFICATION

1. **Case's initials:** _____ _____ _____

2. **Date of interview:** _____ _____ _____ - _____ _____ - _____ _____ _____ _____
   Month   Day   Year

II. ACCESS TO, USE OF, AND ADHERENCE WITH MEDICAL CARE FOR SARCOIDOSIS

Earlier in the interview I asked you about your ability to get health care when you are sick. Now I want to ask you about your ability to get health care for your sarcoidosis.

3. Has sarcoidosis affected your ability to obtain health insurance? ($_1$) ($_2$) ($_3$) ($_4$) **afctabil**
   Yes No Not Applicable Don't Know

   A. **IF YES**, How? _____

4. Has sarcoidosis affected the cost of your insurance? ($_1$) ($_2$) ($_3$) ($_4$) **afctcost**
   Yes No Not Applicable Don't Know

5. If you have health insurance, does your health insurance limit your ability to receive care for your sarcoidosis? ($_1$) ($_2$) ($_3$) ($_4$) **lmtcare**
   Yes No Not Applicable Don't Know

   IF NO, NOT APPLICABLE OR DON'T KNOW, GO TO QUESTION 6.
   IF YES, ANSWER QUESTIONS 5A, 5B AND 5C.

   A. Has it limited your access to a specialist for sarcoidosis care? ($_1$) ($_2$) ($_3$) **lmtspec**
      Yes No Don't Know

      (1) **IF YES**, specify: _____

   B. Has it limited your receiving tests that your doctor thought should be done for your sarcoidosis? ($_1$) ($_2$) ($_3$) **lmttest**
      Yes No Don't Know

      (1) **IF YES**, specify: _____

5. Continued

    C. Has it limited your receiving any medication that your doctor thought you should receive for sarcoidosis?

        ($_1$) ($_2$) ($_3$)   **lmtmed**
        Yes No Don't Know

      (1) **IF YES**, specify: _____

6. During the past 6 months was there any time when you needed medical care specifically for sarcoidosis but could not get it?

        ($_1$) ($_2$)   **need_mc**
        Yes No

    A. **IF YES**, about how many times?   ____ ____ **need_no**

7. If your usual doctor is a specialist, does he or she also provide care for your sarcoidosis?

        ($_1$) ($_2$) ($_3$)   **specprov**
        Yes No Not Applicable

8. In the last 6 months, how many times have you made appointments to see a doctor for your sarcoidosis?

        appt_no
        ____ ____

    A. How many of these appointments did you miss?   ____ ____**misaptno**

    B. If you missed one or more appointments, what was the main reason for the last missed appointment? **INTERVIEWER READ LIST**

        mis_reas

Cost	($_1$)
Lack of transportation	($_2$)
Weather	($_3$)
Other	($_4$)

        IF OTHER, specify: _____

II. MEDICATIONS

9. I am going to read from a list of medications used for treatment of sarcoidosis. As I read each medication, please indicate if you have taken it for your sarcoidosis in the last 6 months.

USE THE BAG OF MEDICATIONS BROUGHT BY THE PARTICIPANT TO HELP IN ANSWERING THESE QUESTIONS

	(1) Generic Name of Medication	(2) Usage			(3) Duration in Months				(4) Frequency		(5) Average Total Daily Dose	(6) Response to Therapy		
		None	Not Current	Current	≤ 6	7 - 12	13 - 24	> 24	Continuous	Off - On		Improve	Same	Worse
A.	Corticosteroid Specify:____	(1)	medusea (2)	(3)	(1)	meddura (2)	(3)	(4)	medfreqa (1)	(2)	____	(1)	medrespa (2)	(3)
B.	Methotrexate	(1)	meduseb (2)	(3)	(1)	meddurb (2)	(3)	(4)	medfreqb (1)	(2)	____	(1)	medrespb (2)	(3)
C.	Azathioprine	(1)	medusec (2)	(3)	(1)	meddurc (2)	(3)	(4)	medfreqc (1)	(2)	____	(1)	medrespc (2)	(3)
D.	Cyclosporine	(1)	medused (2)	(3)	(1)	meddurd (2)	(3)	(4)	medfreqd (1)	(2)	____	(1)	medrespd (2)	(3)
E.	Immunosuppressives Specify:____	(1)	medusee (2)	(3)	(1)	meddure (2)	(3)	(4)	medfreqe (1)	(2)	____	(1)	medrespe (2)	(3)
F.	Anti-malarial Specify:____	(1)	medusef (2)	(3)	(1)	meddurf (2)	(3)	(4)	medfreqf (1)	(2)	____	(1)	medrespf (2)	(3)
G.	Have you taken any other medications for your sarcoidosis within the last 6 months? If YES, answer H - K. If NO, go to Question 10.											Yes (1)	No (2)	med_oth
H.		(1)	meduseh (2)	(3)	(1)	meddurh (2)	(3)	(4)	medfreqh (1)	(2)	____	(1)	medresph (2)	(3)
I.		(1)	medusei (2)	(3)	(1)	medduri (2)	(3)	(4)	medfreqi (1)	(2)	____	(1)	medrespi (2)	(3)
J.		(1)	medusej (2)	(3)	(1)	meddurj (2)	(3)	(4)	medfreqj (1)	(2)	____	(1)	medrespj (2)	(3)
K.		(1)	medusek (2)	(3)	(1)	meddurk (2)	(3)	(4)	medfreqk (1)	(2)	____	(1)	medrespk (2)	(3)

ASK QUESTION 10 ONLY IF CURRENT USAGE OF A SARCOIDOSIS MEDICATION HAS BEEN CHECKED IN QUESTION 9.

10. I would like you to think about how you took your sarcoidosis medicines in the PAST WEEK; on how many days did you:

		Number of Days						
		0	**1**	**2**	**3**	**4**	**+5**	
A.	forget to take some or all of it?	($_1$)	($_2$)	($_3$)	($_4$)	($_5$)	($_6$)	**frgtdays**
B.	not take some or all of it?	($_1$)	($_2$)	($_3$)	($_4$)	($_5$)	($_6$)	**ntakdays**
C.	take more of any of it than your doctor told you to?	($_1$)	($_2$)	($_3$)	($_4$)	($_5$)	($_6$)	**tmordays**

ASK QUESTIONS 11 - 19 ONLY IF CURRENT OR NOT CURRENT USAGE OF A SARCOIDOSIS MEDICATION HAS BEEN CHECKED IN QUESTION 9.

11. Would you say that you take your sarcoidosis medicine just the way your doctor told you to take it? **INTERVIEWER READ LIST**.

All of the time	($_1$)	**curintak**
Almost all of the time	($_2$)	
Most of the time	($_3$)	
Some of the time	($_4$)	
Almost never	($_5$)	
Never	($_6$)	

   IF ALL OF THE TIME, GO TO QUESTION 14.

12. Was there any time you did not obtain your sarcoidosis medication because you could not afford it?

($_1$)	($_2$)	**nomed**
Yes	No	

13. When you don't take all the medication that was prescribed, what is the most important reason for taking less? **INTERVIEWER READ LIST**

	intakles
Forgetful	($_{01}$)
Too busy	($_{02}$)
Didn't need it	($_{03}$)
Side effects	($_{04}$)
Feeling pain, sick	($_{05}$)
Don't think medication works	($_{06}$)
Could not afford prescription/refill	($_{07}$)
Did not have transportation to get the prescription/refill	($_{08}$)
Other	($_{09}$)

   IF OTHER, describe: _____]

14. Has your doctor ever directly asked you about how well you take your sarcoidosis medicine?

(1)   (2)   **intakmed**
Yes   No

15. How confident are you that you can control your sarcoidosis by taking your medicine each day? **INTERVIEWER READ LIST**

Very confident	(1)	**med_cntr**
Somewhat confident	(2)	
Not at all confident	(3)	

16. If you don't take your sarcoidosis medicine what are the chances that something bad will happen to your health in the next year? **INTERVIEWER READ LIST**

Very little chance	(1)	**med_none**
Some chance	(2)	
Fifty-fifty chance	(3)	
Probably will happen	(4)	
Almost surely will happen	(5)	

17. If you don't take your sarcoidosis medicine what might happen?

A.   Don't know   (1)   **dontknow**

B.   Possibly: _____

18. How often do people in your daily life help you by reminding you to take your sarcoidosis medicines? **INTERVIEWER READ LIST**

All of the time	(1)	**reminder**
Some of the time	(2)	
Never	(3)	

19. Most people forget to take their medicine occasionally. How often does this happen to you? **INTERVIEWER READ LIST**

All of the time	(1)	**med_frgt**
Almost all of the time	(2)	
Most of the time	(3)	
Some of the time	(4)	
Almost never	(5)	
Never	(6)	

20. I've asked you a lot of questions. The last question I want to ask is:
Do you think anything caused your sarcoidosis?   ($_1$)   ($_2$)   **src_caus**
                                                               Yes   No

    A.   **IF YES**, what was it?

_____

_____

_____

_____

IV. ADMINISTRATIVE MATTERS

21. **Interviewer:**

    A.   **Signature:** _____

    B.   **ACCESS Staff No.:**   ___ ___ ___ - ___ ___

22. **Research Coordinator:**

    A.   **Signature:** _____

    B.   **ACCESS Staff No.:**   ___ ___ ___ - ___ ___

23. **Date form completed:**   ___ ___ ___ - ___ ___ - ___ ___ ___ ___
                                      Month   Day   Year

FORM 26
Baseline Questionnaire for Cases Only

ITEM	NAME	TYPE (LENGTH)	CODES OR UNITS
	REV	I(1)	Form revision
	newid	F(5.1)	Patient ID
3	AFCTABIL	I(1)	Ability to obtain insurance 1=Yes 2=No 3=Not Applicable 4=Don't know
4	AFCTCOST	I(1)	Affected cost of insurance 1=Yes 2=No 3=Not Applicable 4=Don't know
5 *	LMTCARE	I(1)	Insurance limits care for sarc. 1=Yes 2=No 3=Not Applicable 4=Don't know
5a	LMTSPEC	I(1)	Limited access to specialist 1=Yes 2=No 3=Don't know
5b	LMTTEST	I(1)	Limited tests for sarc. 1=Yes 2=No 3=Don't know
5c	LMTMED	I(1)	Limited medication for sarc. X=Censored
6 *	NEED_MC	I(1)	Could not get care in past 6 mos 1=Yes 2=No
6a	NEED_NO	I(1)	Number of times 1=1 or more
7	SPECPROV	I(1)	Usual doctor/specialist provides care 1=Yes 2=No 3=Not Applicable
8	APPT_NO	I(3)	Appointments for sarc. in past 6 mos 0=0 or Not answered; 8=8 or more
8a	MISAPTNO	I(3)	No. of appointments missed 0=0 or Not answered 1=1or more
8b	MIS_REAS	I(1)	Reason for missed appt. 1=Cost/Lack of transportation 2=Weather/Other
9a2	MEDUSEA	I(1)	Corticosteriod usage 1=None 2=Not current 3=Current
9a3	MEDDURA	I(1)	Corticosteriod duration 1=<= 6 months 2=7 months or more

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* Refer to the form for skip pattern for this item.

FORM 26
Baseline Questionnaire for Cases Only
(continued)

ITEM	NAME	TYPE (LENGTH)	CODES OR UNITS
9a4	MEDFREQA	I(1)	Corticosteriod frequency 1=Continuous 2=Off – On
9a6	MEDRESPA	I(1)	Corticosteriod response 1=Improve 2=Same 3=Worse
9b2	MEDUSEB	I(1)	Methotrexate usage 1=None 2=Not current 3=Current
9b3	MEDDURB	I(1)	Methotrexate duration 1=<= 6 months 2=7 months or more
9b4	MEDFREQB	I(1)	Methotrexate frequency 1=Continuous 2=Off – On
9b6	MEDRESPB	I(1)	Methotrexate response 1=Improve 2=Same 3=Worse
9c2	MEDUSEC	I(1)	Azathioprine usage 1=None 2=Not current 3=Current
9c3	MEDDURC	I(1)	Azathioprine duration 1=<= 6 months 2=7 months or more
9c4	MEDFREQC	I(1)	Azathioprine frequency 1=Continuous 2=Off – On
9c6	MEDRESPC	I(1)	Azathioprine response 1=Improve 2=Same 3=Worse
9d2	MEDUSED	I(1)	Cyclosporine usage 1=None 2=Not current 3=Current
9d3	MEDDURD	I(1)	Cyclosporine duration 1=<= 6 months 2=7 months or more
9d4	MEDFREQD	I(1)	Cyclosporine frequency 1=Continuous 2=Off – On
9d6	MEDRESPD	I(1)	Cyclosporine response 1=Improve 2=Same 3=Worse
9e2	MEDUSEE	I(1)	Immunosupp. Usage 1=None 2=Not current 3=Current
9e3	MEDDURE	I(1)	Immunosupp. Duration 1=<= 6 months 2=7 months or more
9e4	MEDFREQE	I(1)	Immunosupp. Frequency 1=Continuous 2=Off – On

FORM 26
Baseline Questionnaire for Cases Only
(continued)

ITEM	NAME	TYPE (LENGTH)	CODES OR UNITS
9e6	MEDRESPE	I(1)	Immunosupp. Response 1=Improve 2=Same 3=Worse
9f2	MEDUSEF	I(1)	Anti-malarial usage X=Censored
9f3	MEDDURF	I(1)	Anti-malarial duration X=Censored
9f4	MEDFREDF	I(1)	Anti-malarial frequency X=Censored
9f6	MEDRESPF	I(1)	Anti-malarial response X=Censored
9g *	MED_OTH	I(1)	Any other meds in 6 mos 1=Yes 2=No
9h2	MEDUSEH	I(1)	Medication H usage X=Censored
9h3	MEDDURH	I(1)	Medication H duration X=Censored
9h4	MEDFREQH	I(1)	Medication H frequency X=Censored
9h6	MEDRESPH	I(1)	Medication H response X=Censored
9i2	MEDUSEI	I(1)	Medication I usage X=Censored
9i3	MEDDURI	I(1)	Medication I duration X=Censored
9i4	MEDFREQI	I(1)	Medication I frequency X=Censored
9i6	MEDRESPI	I(1)	Medication I response X=Censored
9j2	MEDUSEJ	I(1)	Medication J usage X=Censored
9j3	MEDDURJ	I(1)	Medication J duration X=Censored

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* Refer to the form for skip pattern for this item.

FORM 26
Baseline Questionnaire for Cases Only
(continued)

ITEM	NAME	TYPE (LENGTH)	CODES OR UNITS
9j4	MEDFREQJ	I(1)	Medication J frequency X=Censored
9j6	MEDRESPJ	I(1)	Medication J response X=Censored
9k2	MEDUSEK	I(1)	Medication K usage X=Censored
9k3	MEDDURK	I(1)	Medication K duration X=Censored
9k4	MEDFREQK	I(1)	Medication K frequency X=Censored
9k6	MEDRESPK	I(1)	Medication K response X=Censored
10a *	FRGTDAYS	I(1)	No. days med forgotten 1=0 2=1 3=2 or more
10b *	NTAKDAYS	I(1)	No. days med not taken 1=0 2=1 3=2 or more
10c *	TMORDAYS	I(1)	No. days more med taken 1=0 2=1 or more
11 *	CURINTAK	I(1)	Take medication as directed 1=All of the time 2=Almost all of the time 3=Most of the time/Some of the time/ Almost never/Never
12 *	NOMED	I(1)	Medication not affordable 1=Yes 2=No
13 *	INTAKLES	I(2)	Reason for taking less 01=Forgetful 02=Too busy Didn't need it Side effects Feeling pain, sick Don't think medication works Could not afford prescription/refill Did not have transportation to get prescription/refill Other

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* Refer to the form for skip pattern for this item.

FORM 26
Baseline Questionnaire for Cases Only
(continued)

ITEM	NAME	TYPE (LENGTH)	CODES OR UNITS
14 *	INTAKMED	I(1)	Doctor asks about adherence 1=Yes 2=No
15 *	MED_CNTR	I(1)	Confidence in medication 1=Very confident 2=Somewhat confident 3=Not at all confident
16 *	MED_NONE	I(1)	Chance of bad health without med 1=Very little chance 2=Some chance 3=Fifty-fifty chance 4=Probably will happen 5=Almost surely will happen
17a *	DONTKNOW	I(1)	Don't know what will happen 1=Don't know
18 *	REMINDER	I(1)	People remind to take med 1=All of the time 2=Some of the time 3=Never
19 *	MED_FRGT	I(1)	How often forget to take med 1=All of the time 2=Almost all of the time 3=Most of the time/Some of the time 5=Almost never 6=Never
20	SRC_CAUS	I(1)	Think something caused sarc. 1=Yes 2=No

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* Refer to the form for skip pattern for this item.